

BBS UK Conference 2025

Livestream Programme of Events: Saturday 26th April 2025

**Please note that timings are subject to change*

Time	Activity
9:00am	Livestream starts
9:15am	Welcome Emma Hughes, Chair, BBS UK
9:20am	Update on Gene Therapy Prof Beales, Axovia Therapeutics
9:50am	Therapeutic Approaches for Retinal Dystrophies Robert Henderson, Consultant Ophthalmologist & Vitreoretinal Surgeon, GOSH & Moorfields Eye Hospital
10:20am	Setmelanotide Clinics Update Dr Elizabeth Forsythe
10:45am	Break (20 mins)
11:05am	Planning for the Future – Wills, Trusts and Decision Making Philip Warford, Renaissance Legal
11:30am	Personal Perspective Stefan Crocker
11:50am	Staying Safe Online Sophie Corness, Royal National College for the Blind (RNC)
12:20pm	Update from BBS UK Tonia Hymers, Operations Manager, BBS UK
12:45pm	Break (1 hour 15 mins)

After lunch we will split into two groups for more focused sessions:

People living with BBS will only need to register for the one Zoom link, and they can stay on that link for their afternoon sessions.

Parents/carers of children with BBS will need to register for an additional link to join their afternoon sessions.

People Living with BBS:

Time	Activity
2:00pm	Thinking About Food Kenneth Michie, Dietitian, GSTT Dr Emma McGibbon, Clinical Psychologist, GSTT
2:50pm	The Power of Peer Support Denise Rawden, Retina UK
3:15pm	Comfort break (15 mins)
3:30pm	Communication at a cellular level: An accessible update Dr Emilia Kieckhöfer, Julia Günzler, Cologne, Germany Jannis von Spreckelsen, Viola Kretschmer, Mainz, Germany
4:00pm	Personal Perspective Emily Bartell, USA
4:20pm	Closing Remarks Emma Hughes, Chair, BBS UK

Parents of Children & Young People Living with BBS:

Time	Activity
2:00pm	Supporting Transition to Adulthood Marie McGee, Transition Co-ordinator, Birmingham Children's Hospital and Anna Smith, Rareminds

2:50pm	Cognitive, behavioural and social presentations in children and young people with BBS Dr Gabrielle Blumer and Dr Emma McGibbon
3:20pm	Comfort break (10 mins)
3:30pm	Habilitation: What to Expect in Your Child's Mobility & Independence Programme Suzy McDonald, Habilitation VI UK
3:50pm	Dietary Support Sarah Flack, Principal Dietitian, Great Ormond Street Hospital
4:20pm	Closing Remarks Chetan Meshram, Vice-Chair, BBS UK

Thank you for tuning in to the BBS UK Annual Conference livestream! Recording will be available on our [YouTube channel](#), where you can also watch our past conferences.